



Rethinking disability: Lessons from the past, questions for the future. Contributions and limits of the social model, the sociology of science and technology, and the ethics of care

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► **To cite this version:**

Myriam Winance. Rethinking disability: Lessons from the past, questions for the future. Contributions and limits of the social model, the sociology of science and technology, and the ethics of care. *Alter: European Journal of Disability Research / Alter: Journal Européen de Recherche sur le Handicap*, Elsevier Masson, 2016, 10 (2), pp.99-110. <10.1016/j.alter.2016.02.005>. <hal-01316452>

HAL Id: hal-01316452

<https://hal.archives-ouvertes.fr/hal-01316452>

Submitted on 17 May 2016

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Rethinking Disability: Lessons from the Past, Questions for the Future.

Contributions and Limits of the Social Model, Sociology of Science and Technology, and the Ethics of Care

Repenser le handicap: leçons du passé, questions pour l'avenir.

Apports et limites du modèle social, de la sociologie des sciences et des techniques, de l'éthique du care

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To quote this paper, please use the following reference :

WINANCE, M. 2016. Rethinking disability: Lessons from the past, questions for the future. Contributions and limits of the social model, the sociology of science and technology, and the ethics of care. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap*, 10 (2), 99-110.

Note : this paper has also been published in French, in the same issue of *Alter*.

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Rethinking Disability: Lessons from the Past, Questions for the Future.

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Abstract

In this article, I analyze one evolution in disability research over the past 30 years: the shift from an individual to a social approach to disability. While most disability research has currently “socialized” disability or at the least situates disabled people within a social context, not all do so in the same way nor based on the same assumptions. They lead to different concepts of the person and society and different concepts of disability and normalcy. I analyze this evolution by looking at three approaches to disability: the social model, the approach taken in the sociology of science and technology, and the ethics of care. I show how each, by renewing the analysis of disability, has brought about changes for disabled people and transformed ways of “living together” and “making society.” I also show the limits of these approaches and propose lines of thought for the continuation of our research, notably around the question of autonomy. I propose that we re-think autonomy from the standpoint of the notion of “recalcitrance.”

Keywords: disability, normalcy, autonomy, social model, sociology of science and technology, ethics of care

Résumé.

Dans cet article, j'analyse l'une des évolutions des recherches sur le handicap depuis 30 ans : le passage d'une approche individuelle à une approche sociale du handicap. Si actuellement, la majorité des recherches sur le handicap ont « socialisé » le handicap, ou du moins, situent la personne handicapée dans un contexte social, toutes ne le font pas de la même manière, ni à partir des mêmes présupposés. Elles aboutissent à des conceptions différentes de la personne et de la société, à des conceptions différentes du handicap et de la normalité. J'analyse cette évolution en m'intéressant à trois approches du handicap : le modèle social, l'approche de la sociologie des sciences et des techniques, l'éthique du care. Je montre la manière dont chacune, en renouvelant l'analyse du handicap, a été porteuse de transformations pour les personnes handicapées et d'une transformation des formes du « vivre ensemble », de « faire société ». Je montre également les limites de ces approches et propose des pistes de réflexion pour la suite de nos recherches, notamment autour de la question de l'autonomie. Je propose de repenser celle-ci à partir de la notion de « récalcitrance ».

Mots clefs : handicap, normalité, autonomie, modèle social, sociologie des sciences et des techniques, éthique du care

Since the 1970s, disability research has grown considerably in the various social sciences. An entire field of research was formed (Davis, 2013; Shakespeare, 2015; Watson et al., 2012), either as *disability studies*, notably in Anglo-Saxon countries, or in the form of an interest in disability within certain established disciplines (sociology of health, sociology of science and technology, history of social movements, etc.). While this field of research has remained diverse and heterogeneous in terms of issues, theoretical frameworks, methodologies, etc., it is also built around a shared conceptual evolution: the shift from an individual to a social approach to disability. Initially defended by Anglo-Saxon movements of disabled people (in different forms ranging from the English version centered around oppression processes to the American version centered around rights), this social approach to disability has now become the subject of consensus.

In this article,¹ I examine this evolution by analyzing the contributions and limits of three approaches: the social model (section 1), the sociology of science and technology (section 2), and the ethics of care (section 3). Each of these approaches has its own vocabulary in connection with its theories on disability. In my analysis, I will use the vocabulary specific to each approach and explain it because it is part of the proposed analysis and how it defines the reality of disability. These three approaches have “socialized” disability and by so doing have redefined the notion of disability; however, they have not done so in the same way nor based on the same assumptions. We can therefore question what this “socialization” of disability means and what, in disability, has been socialized. In what follows, I explore how each of these approaches have “socialized” disability, analyzing two aspects. First, I examine how, in redefining disability, each model articulates the natural difference and the constructed (i.e. social) difference, and what each of these differences are. Second, I analyze the standard of reference used by each approach to define the notion of disability and how each approach, by “socializing” disability, modifies the definition of “normalcy.” We shall see that the social model diverges from the other two approaches on this point. The social model, while socializing disability, has not contested the model that has dominated until now—individual autonomy. The other two approaches have, for their part, questioned this preservation of the standard of autonomy as the reference for people’s inclusion in society. They propose conceiving other forms of subjectness for people that,

¹ This article is based on my keynote speech at the 2015 Alter Conference in Paris (July 3, 2015).

what is more, allow them to think about the links between natural and social differences in other ways. By exploring these questions and how each approach handles them, I will show that each has renewed how disability is analyzed and in so doing brought about changes for disabled people. But I will also underscore their limits. Based on this critical examination of these three approaches and, through them, of this major evolution in disability research, I shall discuss in the last section a few lines of thinking for our future research, notably regarding how both individual and social differences and autonomy are analyzed.

1. The Social Model of Disability

I will not give a detailed presentation of this model, which is now well known to researchers working in the field of disability (Barton and Oliver, 1997; Oliver and Barnes, 1998), nor of the debates and criticisms of which it has been the subject (Shakespeare, 2014; Thomas, 2007; Watson et al., 2012). I would nevertheless like to briefly recall the origins of this model and a few of its founding ideas, which the criticism has perhaps led some to forget. The social model of disability was born of an analytic intuition and political claim (Winance and Ravaud, 2011) carried by disabled people that were then formalized under the term “social model.” Their analytic intuition was that disability results from the practices of exclusion, discrimination and oppression to which “disabled people” are subjected. This intuition was based on how they experience disability in their daily lives. It led them to separate the deficiency (an individual biological characteristic) from the disability (a social reality, a position of exclusion defined in relation to the balance of power between people). The socialization of disability is therefore accomplished at the cost of splitting reality into two: on one side, biology, and on the other, society; on one side, a natural specificity (given and inherent to every individual) interpreted in terms of body diversity, and on the other, a social difference (constructed by and resulting from a process affecting certain individuals) interpreted in terms of stigmatization and exclusion. Disability is a social difference piled on top of a natural specificity. In this approach, “social” designated an area of reality and a type of relationship: a balance of power between groups and a labeling process. Thus, one of the major contributions of the social model was to show the structural dimension of disability-related inequalities, and that disability is linked to how society is organized—an argument developed by many researchers.

A political demand was added in addition to this initial analytical intuition: the ability to have the same rights and status as the “able-bodied,” who live independently, in town, work, have families, etc., or who are in other words autonomous. The proponents of the social model make visible and denounce the asymmetry between the positions of disabled and able-bodied people, an asymmetry caused by a process of oppression by the latter of the former (process of domination). They therefore point out the need to reestablish a balance in situations—that is to say the need to give disabled people the same life opportunities as able-bodied people have. While the social model shows the situational and temporary nature of “the ability of the able-bodied”²—linked to circumstances that are both individual and social—it does not challenge the Western standard of the subject, defined as a rational subject able to make his or her own choices—an autonomous subject. In other words, the social model challenges the process of normalization as this process is implemented in the individual model, notably in rehabilitation practices, and in its operational mode, but it does not challenge the normative ideal targeted by this process. Indeed, in the individual model that it opposes, normalization is based on a transformation of the disabled person: it is up to the person to adapt and re-adapt, both to be integrated into ordinary society and be “like everyone else.” Within the social model approach, it is society that, by changing itself, must normalize the person with a disability and make that person an autonomous subject and allow him or her to make his own choices and exercise his or her rights, like everyone else. The process is different, but not the targeted ideal. Yet, this preservation of the autonomous subject as the standard has been criticized by the other two approaches that I discuss in the rest of this article, because it is unattainable for the most severely disabled (notably people with mental disabilities) and because it is exclusive, that is to say it does not allow other forms of subjectness to be recognized.

2. Disability from the Standpoint of the Sociology of Science and Technology

For 15 to 20 years now, disability-related research has developed within the field of science and technology studies (STS). This research is part of this desire to think of disability as social, and has furthermore sought dialogue with the social model of disability (Blume, 2012; Galis, 2011; Law, 1999; Moser, 2000; Pols and Hoogsteyns, 2016 (à paraître)). The

² As we can see in the vocabulary invented by some researchers in this field: “temporarily able-bodied,” “not yet disabled”, etc.

authors in this field apply a methodological principle developed in the sociology of science to disability: the principle of generalized symmetry (Callon and Latour, 1991). This principle supposes analyzing, in the same way and in the same terms, successes and failures, truth and falsehood, society and nature, disability and able-bodiedness (in our case), or abilities and inabilities. These authors thus endeavor to describe empirically and in detail how peoples' abilities and inabilities are defined, and how different forms of subjects can emerge from these configurations. They suspend the idea that an autonomous individual subject exists and ask themselves how this type of subject is formed: through what discourses, which practices, what objects or techniques, etc. Finally, these authors, because of their affiliation with STS, emphasize objects and how they contribute to the emergence of individuals' skills and (in)abilities, or in other words to the definition of what people are and what makes them people. Thus, I. Moser and J. Law have taken a close interest in disability (Law, 2006; Moser, 1999; Moser and Law, 1998), mobilizing one of the theoretical frameworks from the sociology of science and technology: the actor-network theory. I discuss their work below.

Mobilizing the principle of symmetry, I. Moser and J. Law tell us similar stories that they compare, or rather cause to coexist, to reveal their similarities. For instance, they analyze how Andrew, who runs a research laboratory, and how Liv, a young quadriplegic woman who lives alone in an accessible (i.e. suitable for people with physical disabilities) apartment, act in the same way. On the one hand, they explain that Andrew is able to run his laboratory on a daily basis because he is surrounded by computers, machines, employees, etc. that all help give him the "laboratory director" skill. In one of his writings, J. Law notably recounts an anecdote from Andrew's everyday life. One day, Andrew became aware of a problem regarding the most important project in his laboratory: the project had fallen behind schedule. This is what he wrote:

"[The managing director] knows that there is a problem. But let's press this a little further. I want to ask again, how, how does he know? One kind of a response to this question, one kind of narrative, recounts the ways in which figures are put together, with what it takes to make a spreadsheet. This, to tell it very quickly, is a story about computers and computer programs. It is a story about wages and the time-sheets that people fill in at the end of each month to say what they have been working on for the previous four weeks. It is about the

organisational apparatus for collecting those time-sheets, checking whether or not they are accurate, and entering them into the computer” (Law, 1999:10-11).

With this example, the author shows that the knowledge (“there’s a problem with the project”) emerges from the use and combination of diverse resources, heterogeneous—that is to say both human and non-human—entities. The laboratory director is made able to evaluate the delay in the project because he has in front of him a chart, which is itself the result of a series of operations involving people and objects: workers who fill out forms, forms that are compiled by a secretary in software, etc. The director’s skill is supported by all of these operations.

On the other side, I. Moser and J. Law describe the daily life of Liv, quadriplegic from birth, living alone in an apartment. Liv uses an electric wheelchair and various technical aids to handle things in her apartment. She also has other people who come by to help her eat her meals, get up, go to bed, bathe, etc. Again, I quote what they wrote about her:

“If Liv is the person that she is (and she is indeed a formidable person), this is in part because materials of all sorts have been arrayed in and around her life” (Moser and Law, 1998: 3).

“Altogether there are five joysticks. [...] One of these works the environmental control. Click, click, click, this shifts itself through its functions. [...] Liv’s environmental control works a series of functions: it answers the telephone; it makes telephone calls; it switches the lights in her flat on and off; it turns the television on and off; and it operates a series of what they call “apparatuses”. [...] [She] can control the specificities [...] of the television. What channel does she want to watch? How loud should the sound be? [...] Specificities. A command to do this. The capacity to do that. Liv is able, she is able to control the television, to open her front door, and all the rest” (Moser, 1999:2-3).

Liv, like the laboratory director, is made able to know and act thanks to a heterogeneous network that combines humans and non-humans. Liv, like the laboratory director, does not act alone, but by delegating some of this action to objects or other people. Peoples’ abilities are thus defined, in practice and locally, by and within these heterogeneous networks in

which they are included. If abilities are the result of these associations, then inability emerges when there is a gap, when this network does not establish itself, or when it is missing a link. For example, one day Liv wanted to visit her former institution by train, which was usually accessible. On the day of her trip, however, the employees could not find the access ramp, making it impossible for Liv to take the train (Moser, 1999). In this approach, the abilities and inabilities of Liv and Andrew, and more generally of any person, are not given or natural characteristics of people; instead, they emerge from the heterogeneous network made up of human and non-human entities in which the person in question is found. Because they are relative, these abilities and inabilities are therefore always specific.

The interest of this approach within which I have also conducted my research (Winance, 2006) are manifold. Suspending any *a priori* categorization, it makes it possible to show that people, their qualities, their characteristics and their (in)abilities are defined in terms of relationships. This also means that relationships between heterogeneous both human and non-human entities (that these authors call the heterogeneous network) define subjectivity, including the autonomous subject. The qualities of our Western subjectivity—autonomous, centered, articulated, rational—are performed through relationships, in an empirical and local manner. But there are other forms of subjectivities: passive, decentered, silent, etc.

This approach calls into question the normalcy of the Western subject, and does so in two ways. First, it does so by showing that peoples' capacities to act and subjectivity are not located in a naturalized able body, but in a network of relationships with other entities. Second, by showing that different forms of subjectivities emerge from this network of relationships, it suggests the idea that all human people define themselves and are defined by assembling several of these forms, of which only some correspond to the autonomous subject standard. In this conceptualization, the single standard of the autonomous subject disappears, leaving room for the diversity of types of subjectivities that make up people and the differences between them. We are all more or less able,³ but in a specific and situated, concrete way. "Disability" does not result from any essential, absolute difference; as in the social model, it is the result of the relationships in which people are involved, and above all it is redefined in terms of abilities and inabilities. This approach therefore goes further than the social model because it both challenges the standard of "able-bodiedness" and

³ This affirmation is found in other social approaches to disability, notably the universal model of disability.

deconstructs certain distinctions that the social model maintains such as nature/culture, biological/social, body/mind, etc. It also proposes a broader and performance-based definition of socialness. Social simply designates the association of entities, regardless of their nature, that all participate in defining the collective and the qualities or abilities/inabilities of the person.

However, the analysis proposed by this approach has certain limits. The juxtaposition of anecdotes recounted by I. Moser and J. Law, while it is striking and makes one think, is also problematic inasmuch as it shows inequalities, or to use their terms, asymmetries that are not analyzed. I. Moser and J. Law put into parallel the story of a laboratory director (who they do not explicitly say is able-bodied) and that of a person in her daily life (a person explicitly presented as disabled). The contrast between the two situations, despite the symmetrical analysis (perhaps even because of it), is striking: on the one side there is a person who works and on the other a person at home; on one side there is a person who during the day will have gotten up, gotten dressed, traveled X kilometers to go to the office, and accomplished a certain number of tasks—reading and writing documents several pages long, meetings, research, etc.—and on the other, there is a person who during the same time will have gotten up, gotten dressed, and written one or two pages of the biography she has started to write. If we use their terms, the least we can say is that we are facing two very different specificities, for which the “difference” is silenced. The term “difference” designated an inequality in social position, but also the complexity in modes of action, which transform what a person is, his or her body, identity, and life possibilities (Winance, 2006). Yet, if this difference is silenced, ultimately it is because the approach through STS cannot explain it, or can only explain it *a minima*. The difference between disabled people and able-bodied people lies in the fact that, for the latter, their “standard” body matches the construction standards of the heterogeneous networks that make up our society; it is therefore easier for them to acquire the status of autonomous and independent subject. Disabled people, for their part, must face many gaps and therefore have a harder time making themselves into autonomous subjects (Moser, 2000). Finally, we can wonder and ask if this does not send us back to the social model and its hypothesis of exclusion and oppression of disabled people. In other words, by reducing the symmetrical analysis of disabled and able-bodied people to an analysis—albeit symmetrical—of only abilities and inabilities, this approach dilutes difference in specificity (each person is specific and unique)

and along the way loses the “disability,” that is to say both the inequality of social positions and the definition of qualities and identities that are not infinitely flexible and may be experienced positively or negatively.

3. The Ethics of Care

The ethics of care approach is, for its part, a movement that grew out of philosophy (Gilligan, 1982; Tronto, 1993). It formed in the 1970s at the same time as disability studies, which adopted a critical stance in its regard (Fine and Glendinning, 2005; Finkelstein, 1998; Morris, 1997) before seeking dialogue (Beckett, 2007; Damamme, 2012; Keith, 1992; Kröger, 2009; Watson et al., 2004; Winance et al., 2015). The ethics of care movement contains a diverse range of approaches and has given rise to major debates, that I will not review here. I shall simply emphasize some ideas that seem to me to be shared within this movement, before focusing on one of its authors who has worked more specifically on the issue of disability, Eva Kittay.

According to the ethics of care approach, the common point among all human beings is that at one time or another in their lives, they need to receive care from others to live: every human being starts as a baby dependent on its parents for its life and everyone, during their lives, may at any time find themselves dependent on or vulnerable⁴ to others. This state of dependency is not seen negatively here as a state of domination or subjection⁵ but rather positively as generating care. This state of dependency opens the possibility of a specific moral existence, learning and the attainment of values linked to care, values that are distinct from those linked to justice. The term “ethics” comes from this dimension: preserving the relationships that form us is a moral stake equal in importance to that of justice. This approach calls into question the figure of the autonomous and rational subject existing by itself, which it presents as a normative ideal and pure fiction, and defends the idea of a relational subject formed through care relationships. It therefore redefines autonomy in a relationship-based and sensitive manner. All autonomous subjects have also at some point been and still are dependent subjects involved in emotional relationships. In this vision, it is therefore not a matter of opposing “autonomy” and “dependency” but of showing how care relationships and dependency underlie autonomy.

⁴ A term frequently used in this approach.

⁵ In the disabled people’s movement and the social model, dependency is analyzed in terms of domination.

“Analysis of care has the virtue of showing the permanency of care activities underneath the reassuring image of a society made up of competent, equal, autonomous adults in good health” (Paperman, 2005:291).

In the rest of this section, I focus on one of the authors in this movement, E. Kittay (Kittay, 2005; Kittay, 2011; Kittay, 2002). She works within this movement and is extending it through the issue of disability (Garrau, 2015). E. Kittay’s thinking is anchored in her personal history: she is the mother of a person with severe physical and mental disabilities who is dependent on others for all acts of her daily life.

“My daughter, a sparkling young woman, with a lovely disposition is very significantly incapacitated, incapable of uttering speech, of reading or writing, of walking without assistance, or, in fact, doing anything for herself without assistance. She has mild cerebral palsy, severe intellectual disability, and seizure disorders. Although her cognitive functioning appears limited, she loves music, bathing, good food, people, attention, and love. (Some of the finest things life has to offer.) She is fully dependent and while at the age of 40 she (like us all) is still capable of growth and development, it is quite certain that her total dependence will not alter much” (Kittay, 2011:54).

This passage shows a contrast with the quotes from the STS given above. In it, E. Kittay describes both what her daughter can and cannot do. However, unlike the analysis of I. Moser and J. Law, which places abilities and inabilities into symmetry with each other, the description written by E. Kittay pinpoints a certain difference between “what Sesha can do” and “what Sesha cannot do.” This difference can be seen in the type of language used to talk respectively about Sesha’s inabilities and abilities. On one side, Sesha *is incapable* of writing, walking or speaking; on the other, she *loves* music, good food, attention, love... On one side, there are functional inabilities and deficiencies, and on the other, emotional or affective possibilities. The person is seen from the get-go through several dimensions, each potentially carrying meaning and value, different definitions of normalcy.

In this passage, E. Kittay also insists on the state of extreme dependency in which her daughter finds herself. This state of dependency is extreme because it will not lead to a situation of interdependency in which the roles of care receiver and care giver can switch. Yet, the experience of caring for a completely dependent person who will remain so is the

starting point for E. Kittay's analysis and leads her, in regard to the ethics of care, to insist on several points. First, she points out the positional asymmetry between the person cared and the carer, but shows that this does not necessarily generate a relationship of domination. On the contrary, vulnerability is a condition shared by both people: the person who takes care of the other is placed in a position of secondary vulnerability because he or she must place him- or herself at the service of the other, listen to the other, and efface him- or herself. This vulnerability is all the stronger when the other's dependency on him or her is considerable. Inversely, the care relationship can potentially generate dignity for both people, the care receiver and the care giver. The value of life and the value of each individual are created in and by these care relationships.

Recognizing the inevitable dependency generated by certain forms of disability—as one form of dependency among others—then allows one to recognize that these people are full members of the human community. E. Kittay proposes conceiving normalcy not based on the Western subject, and not based on the capacity to decide or do independently, but rather based on people's capacity to enter into and be involved in care relationships (Kittay, 2006) or more broadly relationships of love, "of enjoying reality" (Kittay, 2015). E. Kittay analyzes all the ambivalence found in the question of normalcy or rather the desire for normalcy in a nuanced manner. People's ability to love is linked to the fact that they themselves are loved, as unique individuals. This means that they are loved for themselves, in their difference and with their difference, but also in what is "normal" about them and how they normalize those who take care of them. E. Kittay explains, for example, how her husband, son, daughter and herself form a *normal* family. Sessa—while very different from other children—was no less a child that made E. Kittay into a mother and she, like her mother, loves her child:

"But we had immediately fallen deeply in love with our sweet, beautiful Sessa and I felt very much like a normal mother—one who would not consider giving up her child, discarding a child because she didn't meet someone's expectations of what a child should be. In this, my normality as a mother normalized my child. We wanted to live normal lives and be a normal family, not by excluding my non-normal daughter, but by creating our own sense of normal" (Kittay, 2006:92).

Creating their own sense of normalcy implied complying with some aspects of normalcy and transforming others.

“When parents of a disabled child insist on the normalcy of their special position as parents, they affirm the desirability of normalcy. But what they affirm is an altered concept of the norm” (Kittay, 2006:102).

For E. Kittay, normalcy is not only relative, linked to care relationships, but also altered because it includes the difference and uniqueness—we could say the otherness—of the person.

Finally, the recognition that we all are born dependent and we all need care is the foundation of a social and moral obligation: we should all receive the care we need. Social justice then flows from a twofold condition: equality of access to care and society’s support of care givers. The way in which E. Kittay conceives socialness goes beyond the simple idea, supported by STS, that socialness arises from the relationship between or association of heterogeneous entities. Her concept of socialness is linked to her concept of justice and leads her to question the nature of the relationships that make up society.

The contributions of this approach, here mainly addressed through the work of E. Kittay,⁶ are also manifold. This makes it possible to open the register of humanity and include different forms of normalcy, or rather to alter what normalcy is without losing it. It makes it possible to conceptualize the specificity of disability without diluting this specificity in the (equally defended) argument that we are all dependent on others and all vulnerable. However, it also has certain limits. The normalization of severely disabled people, in E. Kittay’s thinking, refers to the recognition of these people as moral people and their inclusion in the moral community. It is done by the care relationship and in the emotional field. Thus, two registers of normalization (recognition and inclusion) seem to coexist: that of reason and that of emotion, even though both are relative (resulting from the care relationship). A severely dependent person is situated in the emotional register. Thus, unlike the sociology of science and technology approach, this approach does not make it possible to reveal the way in which the person, even when severely dependent, can be made capable and autonomous, can change register or form of subjectness, and can move into the register of reason. Yet, the demand of autonomy for all runs through the disabled person’s movement, and it needs to be taken into account.

⁶ Whose stances are distinguished from those of other care theoreticians.

4. Paths for Future Research: Difference and Autonomy at the Heart of Disability

In this article, I have analyzed how, for 30 years, disability research has socialized disability and in so doing lead to different concepts of the person and society, and of disability and normalcy. While the social model integrated “socialness” by differentiating two realities: deficiency and disability, with only the second being considered to be “social,” other approaches have conceived disability based on the relationships between people, or as in STS, between humans and non-humans. In this last section, I would like to discuss two challenges in this evolution.

The first challenge is how this evolution could lead to a way out of the debate, both analytical and political, between the essentialist approach and the constructivist approach to disability. The medical model as it has been caricatured by the proponents of the social model came from a “pure” essentialist approach, that is to say one that considered disability to be a natural reality and essential difference. The integration of this difference ultimately relies on the humanity and generosity of the “able-bodied.” In opposition, the social model proposed a purely constructivist position: the disabled person is one that is placed in this position by society or who adopts this position to defend his or her rights (Winance and Ravaud, 2011). Disability is purely social, and its elimination comes from transforming society. Deficiencies are individual characteristics among others, not significant, not meaningful. In so doing, this approach loses the nature of the experiences of disabled people, as certain critics, notably disabled feminists, have argued (Corker and Shakespeare, 2002; French, 1993; Shakespeare, 2014).

The two approaches discussed afterwards, that of STS and the ethics of care, provide a way out of this debate. The STS approach, taken by I. Moser and J. Law, leaves it by analyzing how abilities and inabilities are produced in heterogeneous networks. Thus, there are only specificities and relative differences, but no essential differences. From the political standpoint, it is no longer a matter of reducing or eliminating the disability, but of describing the diverse forms of subjectivities, the diverse ways of being able or unable, and the diverse ways of doing and living. It is a matter of making visible and palpable the entities, both human and non-human, that are not or cannot be able by themselves. Because to describe is to do (it is performative): describing allows one to give life to these alternate forms of subjectivities and therefore transform the collective. However, in their approach there is an underlying and constant optimism that means that “everything stays flexible” and

differences never become striking or pronounced, positive or negative, naturalized or naturalizing.

E. Kittay's position is similar but different, because she takes the argument further. She asserts that people do not have intrinsic dignity. Each person's dignity—whether they be care receiver or care giver—is produced within the care relationship. In other words, it is the care relationship alone that performs, or produces, the intrinsic value of each person (a value that he or she therefore does not have outside this relationship), and does so in the positional difference. From the political standpoint, this has led her to prone an attentive—"caring"—society that meets the needs of each individual, care receiver or care giver.

The two approaches therefore exit the "essentialism *versus* constructivism" debate by explaining how a person's nature emerges from the relationship. I think that it will be necessary to continue along this path to reach an understanding of how—beyond the simple variations in specificities ("we are all more or less capable, disabled, in space or in time")—differences, both positive and negative, are thus naturalized, fixed, defined, and probably defining, fixing and naturalizing. An analysis of these differences is necessary to find the drivers of political transformation.

This point leads me to the second challenge that I would like to address in this discussion. It is the way in which the political question plays out in this debate: what is the standard of reference used to recognize a person as normal, that is to say as a person who has both specificities that define him or her as unique and specificities that identify him or her to others—that make him or her a person "like everyone else"? Yet, as I explain above, the meaning of what it is to "be normal" is different in each approach. For the social model, normalcy is still defined in reference to what the able-bodied can do: work, have a family, etc., and behind this model of "able-bodiedness" is the autonomous subject as a reference. STS questions the idea of normalcy as a quality defining people, and show that normalcy resides in the flow of actions, which are always the result of local, specific, etc. arrangements made up of heterogeneous human and non-human entities. For the ethics of care, as developed by E. Kittay, normalcy refers to the emergence of a person as a moral person in and through care relationships, which proves his or her similarity to others while leaving room for the expression of his or her differences.

The shift from an individual to a social approach to disability has thus led to the contestation of the normativity of the Western autonomous subject (by showing the

existence of other forms of subjectness) and the deconstruction of this subject (by showing that autonomy is created by and in relationships). This evolution has, in recent work,⁷ taken the form of the emergence of the notion of relational autonomy (Mackenzie and Stoljar, 2000b; Keyes et al., 2015). This notion designates the idea that autonomy is conditioned by the social relations in which individuals are embedded. C. Mackenzie and N. Stoljar suggest reconfiguring the notion of autonomy based on the feminist criticisms of the traditional concept of autonomy.

“The critiques emphasize that an analysis of the characteristics and capacities of the self cannot be adequately undertaken without attention to the rich and complex social and historical contexts in which agents are embedded; they point to the need to think of autonomy as a characteristic of agents who are emotional, embodied, desiring, creative, and feeling, as well as rational, creatures; and they highlight the ways in which agents are both psychically internally differentiated and socially differentiated from others” (Mackenzie and Stoljar, 2000a:21).

This challenging and reconfiguration of the notion of autonomy by the various social approaches has opened possibilities for people in terms of ways of being for themselves and in terms of ways of living in society. This evolution seems to me, however, to lead to certain political and analytical difficulties. Politically, this evolution either transforms the very nature of autonomy or reserves it for certain people. While I agree with the objections to autonomy as the only normative register and on the need to describe other normative registers, arguing that some people will never have access to autonomy is problematic. Particularly since the authors ultimately say relatively little on possible alternative registers, merely describing them briefly with the terms “passivity,” “emotion,” “affect,” “pleasure,” etc. This is certainly a path to explore, but not the only path. Analytically, using the term “relational autonomy” seems to mask certain questions. First, autonomy—even when it emerges from relationships—does not seem to be built in just any relationship, but in relations of “confrontation”, “rupture” or “separation.” In other words, this notion must lead us to question the nature of relationships that lead to autonomy. Second, and perhaps more radically, must we not question the very meaning of the notion of autonomy, which refers to

⁷ For instance, many of the submissions received in response to the call for “care and disability” articles for the journal *Alter* (issued in October 2013, which resulted in two issues of the journal, Nos. 9(3) and 10(1)), discussed the notion of “relational autonomy.”

decision-making capacity and more broadly to the normative capacity of individuals? Is people's ability to decide, or position themselves, separate themselves not linked above all to this normative capacity? Have we not gone too far in the socialization of disability? Have not the "social" approaches to disability forgotten certain realities, and is it not time to once again shift our focal point and conceive autonomy based on this normative capacity and the notion of separation instead of seeking to understand autonomy through relationships?

In the 1970s, disabled people demanded their autonomy by saying "no" to what was done to them (even though that was later criticized because it was ultimately seen as excluding certain disabled people). They asserted *their autonomy* as a breaking away from professionals, institutions and existing care systems while identifying with a group of disabled people. Autonomy emerged in a *break away/regrouping movement*. Similarly, if we look again at babies' situation, used in the ethics of care, babies are of course born dependent and vulnerable, but they have another quality, another ability—the capacity to resist in one way or another (by crying, gestures, refusal to do, etc.), show their discomfort and disagreement, etc. to influence how their mothers and fathers take care of them. Just for once, I will call on my own life. I have a four-year-old daughter. She does not like riding in cars because she hates being restrained in her car seat. Until very recently, she was able to scream for 800 km. From my position as mother, this behavior was totally irrational and much more tiring for her, and for us, than to wait in silence as the kilometers went by. But it was her way of resisting at a stage in her development when she did not have any other way to express her disagreement. I believe that even the most severely disabled people have this capacity to resist, this capacity at certain moments to show their disagreement. Is autonomy not found in this capacity people have to resist, in this capacity to be *recalcitrant*?

Here I refer again to the sociology of science and technology and B. Latour (Latour, 2000) who uses I. Stengers' term "recalcitrant" (Stengers, 1995) to explain scientific objectivity. *Recalcitrance* is the ability of objects, within an experimental system set up by a researcher, to object, to produce unexpected responses to the question asked by the scientist. In other words, *recalcitrance* is objects' capacity to not comply with researchers' expectations, demands or hypotheses. People also have this capacity for *recalcitrance*, but are more inclined to abandon it. And yet, is this *recalcitrance*—which emerges in relationships—not the mark of the subject, of the person who resists what is offered in this relationship? For me, it is a form of what we could call "raw autonomy." Going back to the

example with my daughter, her behavior was a relatively efficient way to show her disagreement, let us know what did not match her wants, and get us to change our way of vacationing because for the first three years of her life we vacationed 100 km from home. While her behavior was irrational from my point of view, it was not from hers. Is not the challenge of the care relationship—and more broadly all relationships—to succeed in (as scientists attempt to do in designing their experiments) giving form to this autonomy, that is to say make each person’s “reason”⁸ (his or her own interest) speak and act? It would be a matter of articulating, in and by the relationship, the capacity to detach and act by oneself. What is more, this is what many care givers do in their daily practice. For me, the challenge for our future research is notably to analyze the conditions or experimental set ups (to continue the analogy with the sociology of science and technology) that make it possible to cultivate each individual’s *recalcitrance*, that is to say each person’s capacity to say unexpected things, object, propose ways of living together, reach agreements, or even develop new qualities and thus become autonomous. This notion of autonomy must, of course, be used with tact to avoid falling into an “injunction to do”, which would be contestable. But yet, by making autonomy relational, must we erase the strength it has historically had within the disabled people’s movement? At this stage in my reflections, this is something I ask myself.

Declaration of Interests.

The author declares no conflicts of interest.

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⁸ Here, “reason” refers to one’s motivation, and not one’s thinking or intelligence.

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